Vol. 6 No. 2

January 1995

NEW STAFF AT ASCC

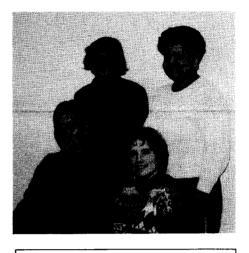
The Fall brings many changes and it brought several staff changes to the AR Spinal Cord Commission Central Office. The new faces at the right match the new voices you will hear when you call our offices these days.

SPINAL CORD

Jan Maness, CRRN, BSN, joined us in October as the Project Coordinator for our Secondary Conditions in Spinal Cord Injury project. Jan is working 25% time on the project at the Commission; the rest of the time, she serves as the SCI Clinical Specialist at Baptist Rehabilitation Institute. In her "free" time, Jan is completing her Masters degree at UAMS. A busy lady, we are glad to have her working with us on this exciting new project.

Rebecca Myrick also joined ASCC in October as our Research Analyst. In this role, Rebecca works on the Registry and several research projects, including the secondary conditions survey. A native Arkansan, Rebecca completed her Masters degree at Auburn University. Previous to coming to the the Commission, Rebecca was the Coordinator of Institutional Research at Columbus College in Columbus, GA. Rebecca's research and computer skills and experience are already expanding the scope of ASCC's Research Department.

Denise Roulhac was our third addition to the ASCC staff in October. If you call the Little Rock Continued - see "New Staff" on Page 8



New ASCC staff, left to right, are Jan Maness, Denise Roulhac, John Gould and Rebecca Myrick.

ANNUAL CONFERENCE TO BE HELD ON JUNE 3

Mark your calendars! In response to many requests for a weekend meeting, the Sixth Annual ASCC Conference will be held Saturday, June 3, 1995. We will be returning to the C.A. Vines Arkansas 4-H Center in Ferndale.

We are presently requesting input and suggestions from our Spinal Courier readers on topics, presentations and speakers for the conference. If you have a question or an interest you would like to have addressed at the conference, or if you know a dynamic speaker who could make a presentation on an SCI-related topic, please send them to: Conference Program Committee, ASCC, 1501 North University, Suite 470, Little Rock, AR 72207. We will finalize the program in February, so please send in your ideas by Feb. 10th!

AGING AND SCI: WEIGHT GAIN AND PAIN

What happens when able-bodied people gain weight? They become less active, lose self-esteem, and place themselves at higher risk for heart attack, stroke, respiratory ailments, clogged arteries, diabetes, renal and gall bladder disease, arthritis, and some kinds of cancer. What happens when people with spinal cord injury (SCI) gain weight? All the above and, potentially, lots more.

This is not to say that large numbers of older people with SCI are gaining weight and having dire problems. According to the 1993

Craig/British Aging Study of 282 survivors (all injured for at least 23 years and some as many as 50) average weight gain has been quite modest. But for those who do gain excess pounds, repercussions can be serious. Effects can include injury and, consequently, loss of function, recreational and career opportunities, independence, and quality of life.

Unnatural Acts

The ordinary day-to-day realities of living with SCI demand more of people. For example, individuals normally use their hands and Continued - see "Aging and SCI" on page 6

SPINAL COURIER

Published quarterly by Arkansas Spinal Cord Commission

Cheryl L. Vines Executive Director

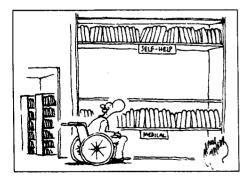
Thomas L. Farley
Dee Ledbetter
Co-editors

The Arkansas Spinal Cord Commission does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

BUCKLE UP!

NEW RESOURCE CENTER MANUAL

The new Resource Center manuals are in! Anyone interested in step-by-step training for using the ASCC Education and Resource Center on SCI should contact Karen Schmidt for an appointment at 296-1792, Mon. to Fri., 8:00 to 4:00. A wealth of information can be yours free for the asking - take advantage of it!



PN/May 1992

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

COMMUNITY WEIGHT CLASS

Dear Editor:

Baptist Rehabilitation Institute is currently exploring options for a weight class open for spinal cord injured individuals in the area. Proposed time for the class would be 4:00 - 6:00 p.m. Tuesdays and Thursdays. The fee would be \$5 monthly, however special arrangements can be made if necessary. Transportation is not provided. Implementation of the weight program is dependent on interest displayed.

If you are interested, please call 223-7520 and ask for Maly Jackson, OT; Kim Chowning, PT; Adrienne Shelton, OT; or Lisa Anderson, PT.

Kim Chowning, PT Baptist Rehabilitation Institute Little Rock, AR

WELL SPOUSE FOUNDATION

Dear Editor:

The October 1994 issue of *Paraplegia News* had information on the Well Spouse Foundation that maybe of interest to some family caregivers.

This organization provides support groups, a newsletter and a roundrobin letter writing club. The focus is on providing support for caregivers whose needs are often forgotten. For more information, please contact the Well Spouse Foundation, P.O. Box 801, New York, NY 10023.

The writer, Sharon Scerrato, is a

"significant other" for a quadriplegic, and she was very complimentary of the support from the Well Spouse Foundation. Our caregivers may benefit as well.

Robert Griffin, ASCC Case Manager Russellville, AR

GET YOUR FLU VACCINATION

Dear Editor:

I wanted to take a minute to ask the Spinal Courier readers: have you had your Flu Vaccine for this year? If not, you should have had it in October or November, but it still isn't too late! Contact your physician or your local health department.

Shirley McCluer, MD ASCC Medical Director

SUPPORT GROUPS

Dear Editor:

Why is it every time you hear the words "support group" you automatically think of a whining or complaining session? A support group can mean many different things to many people. To me, a support group is something that takes only one hour per week and is a place where I can feel free to discuss any subject I want, plus it gives me a chance to meet new people and exchange ideas to make life a little easier. A support group can really do wonders for your self-esteem; so why don't you give it a try!

Karen Schmidt, VISTA ASCC Educ. & Resource Ctr.

HIGH PROFILE!

BETTIE TAPP

This is the sixth in a series of articles profiling the ASCC Case Managers.

If there is a successful, well attended Fall outdoor recreation event going on around Lake De-Gray you can be sure Bettie Tapp is involved. For the past five years Bettie Tapp has coordinated such an event for individuals with spinal cord disabilities and their families. Because of Bettie's planning skills and coordination of events, the "Fall Foliage and Fun Day" has become the best attended ASCC recreation event in the state. In order to assist others with such endeavors, Bettie and her fellow Case Manager Charles Crowson have developed an "Outdoor Recreation Planning Guide" which is now part of the ASCC Case Management Services Procedures Manual.

When she is not planning recreational activities, Bettie spends many endless hours providing case management services to the 176 ASCC clients in Montgomery, Saline and Garland counties. She is an excellent advocate on behalf of those clients and believes strongly in each individual's worth and dignity. It is these qualities which enable Bettie to quickly gain the respect of the individuals she serves.

Bettie obtained her BS and MSE from Henderson State University. Prior to her employment with ASCC, Bettie provided 18 years of enthusiasm and dedication to the public school systems in the Hot Springs area. Those traits and a strong desire to continue assist-

ing people in need eventually led Bettie to choose Case Management as a career.

Throughout the years Bettie has served on numerous organizations and committees on the local, state and national levels. She is a past Board Member of the Arkansas Rehabilitation Association and has been trained as an Accessibility Surveyor by the National Rehabilitation Association. Bettie, like many of the other ASCC Case



Managers, often receives requests from local businesses, schools and other agencies to provide technical assistance on accessibility.

Many of Bettie's clients and coworkers might describe her style as determined and persistent, and very appropriately so. However, the phrase, "I will find a way, or make one," seems more fitting and definitely captures her philosophy.

FAMILY MEMBERS: Husband, Charles; daughter, Chrystal; son and daughter-in-law, Tylar and Mandy.

PHRASE TO SUM ME UP: Wherever I go, there I am.

FAVORITE WAY TO UNWIND: Listen to soft music, walk in the woods or watch the ocean roll in and out.

IF I COULD GO ANYWHERE IN THE WORLD, IT WOULD BE: Alaska and Australia.

MY GUIDING PHILOSOPHY: Not to look death in the face before I learn to live.

MOST PRIZED POSSESSION: Friendship is my most valued possession. Friendship is priceless and should be treasured.

MOST SIGNIFICANT ASPECT OF MY JOB:

Working as a team member with my clients. We develop a rapport that allows us to produce innovative ideas that improve the situation. We work as a partnership with each of us sharing responsibilities.

ADVICE TO SOMEONE CHOOSING CASE MANAGEMENT AS A CAREER: Listen to your clients.

MY BEST ADVICE TO SOMEONE WITH A DISABILITY: Choose what you want to do next, and begin.

FROM THE DIRECTOR

Happy New Year! Are you ready for a new year? New beginnings? New challenges? I think that I am. It is always refreshing to me to turn over the page on a new calendar and start the new year - even though lots of the same old projects and problems move along with us, the idea of starting anew feels good to me.

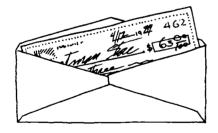
We're off to a bounding new start here at the Spinal Cord Commission. As you read through these pages you'll see that we have new staff (and lots of great "old" staff), new research projects, our annual conference, and lots of challenges for 1995.

The new year has also brought a new legislative session, with more challenges for finding and preserving funding for services that folks with disabilities need. Funding for the Spinal Cord Commission's budget for the next two years will also be decided. We have received recommendations from the Governor and the Joint Budget Committee (thanks to the support of Representatives Dennis Young and Butch Calhoun) to increase our client service funds and our long term attendant care program. We now begin the process of getting approval and fund allocations. Your Senator and Representatives will be voting on this appropriation over the next two months. Your support is always helpful.

I'm excited that our secondary conditions survey is almost ready to start. If you have a spinal cord injury, expect a call or visit from your Case Manager over the next few months to interview you for this study. It takes about an hour; all you do is answer questions about your experiences with spinal cord injury and the medical and other complications that come with it. The results of the study will be complete about this time next year and we'll be sure you read about them here in the *Courier*.

Thanks in advance for your help in this study! And enjoy the challenges of 1995!

Cheryl Vines



The Arkansas Spinal Cord Commission accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and

If you would like to make a contribution, please contact the Com-

educational resources.

WITH THANKS

mission or send your donation to:

AR Spinal Cord Commission, 1501 North University, Suite 470 Little Rock, AR 72207.

FOURTH QUARTER DONATIONS

In Memory of Larry Whittle:
Patricia Bonner
Alice Bradford

NEW ITEMS IN THE ASCC EDUCATION & RESOURCE CENTER ON SPINAL CORD INJURY



Arkansas Parks -Adapting Outdoor Adventures

A new brochure is now available in the ASCC Education and Resource Center on SCI, Arkansas Parks - Adapting Outdoor Adventures. This is a complete guide for visitors with disabilities to all Arkansas state parks. Please contact Karen Schmidt at 296-1792 if you would like to obtain a copy or need more information.

New Children's Book

The Center also has a great new book aimed at children, Rebecca Finds a New Way. Written by Connie Panzarino and Marilyn Lash, this book illustrates how to teach kids to learn, play and live with SCI and other disabilities. You may check it out of the ASCC library; or to obtain your own personal copy, call toll free 1-800-962-9629 or write:

Nat'l Spinal Cord Injury Association 600 W. Cummings Park, Suite 2000 Woburn, MA 01801

ABNORMAL SWEATING IN SPINAL CORD INJURY

One of the less serious, but very annoying complications following spinal cord injury (SCI) is abnormal sweating (unrelated to the normal sweating that occurs when a person gets too hot). The causes for this sweating are very poorly understood. The effects can be severe enough to affect bladder and bowel function due to dehydration from loss of water.

Evaluation: Before attempting any kind of treatment, each person should be carefully evaluated to see if a specific cause for the abnormal sweating can be determined. Attention should be given especially to where and when the sweating occurs.

Location of the Sweating: It may occur everywhere on the body, or only in specific areas. It tends to occur above the level of the spinal cord injury (on face and shoulders) in quadriplegics and high paraplegics, and mostly below the level of SCI (on legs and trunk) in lower paraplegics. It rarely occurs in cauda equina injuries.

When Does It Occur? In some individuals it occurs usually at night, and in others it is mostly during the day. It may be related to bladder emptying, constipation, position, etc. The sweating

can be continuous, or intermittent, or there may be no pattern at all to when it occurs.

Autonomic Dysreflexia: Probably the most common cause is autonomic dysreflexia. This is a syndrome that occurs in quadriplegics and high paraplegics (SCI level at or above T-6). The sweating is a response to some stimulus below the level of injury, such as bladder spasms, tight clothing, pressure sores, etc. The treatment in these cases is to identify the cause of the dysreflexia and eliminate it. For more information about dysreflexia, contact the Spinal Cord Commission.

Treatment: If the cause of the sweating can be identified and eliminated, the treatment is simple. However, for those of you who have tried everything and have been unable to find a cause, medications may be necessary to control the sweating. It should be recognized that all of these medications have an effect on other body systems also and potential side effects should be well understood and watched. This includes especially blood pressure and bowel or bladder function. A prescription is required for all of these medications.

Inversine (Mecamylamine)
 5 mg., once or twice a day. This



should be tried first because it is least likely to have side effects. It will be obvious within 2-3 days whether or not it is helping. If it does not help, discontinue this medication.

2. **Darvon 65 mg.** once or twice a day. It should be plain Darvon, not Darvon compound or Darvocet. It is not clear why this medication works, but it does.

In my experience, patients who responded to one of these two medications did not respond to the other, and vice-versa. Since Darvon is considered to be a narcotic, it should not be used as the first choice. Most cases have responded to one of these two medications.

3. Transderm Scopolamine (skin patch) 1.5 mg. Although I have no experience with this, it has been reported by others to be very effective with no side effects. The patch is worn continuously and changed every third day.

If anyone has found other treatments to be effective, please let me know so I can add them to my list.

UPDATE ON SECONDARY CONDITIONS PROJECT

The Secondary Conditions Project mentioned in the October 1994 issue of the Spinal Courier is well underway. Since its formation in October, the research team has worked diligently and a survey instrument has been developed. In January 1995, an advisory panel comprised of nationally recognized authorities in spinal cord injury (SCI)

research came to Little Rock to provide their thoughts about the survey.

In February, the research team will meet with all the ASCC Case Managers to brief them about the survey instrument and procedures. From March through November the Case Managers will administer the survey to their respective

clients who have a SCI. If you are asked to respond to the survey, the research team requests your cooperation and says "thank you" for your participation in this important study.

Future editions of the *Spinal Courier* will continue to monitor the progress of this timely project.

AGING AND SCI

Continued from Page 1

arms for reaching and grasping. But after SCI, people rely on them for wheeling and transfers, even if the upper limbs are weakened or partially paralyzed. Crutch walkers, too, subject their muscles and joints to unnatural and sustained strain. So hands, wrists, arms, and shoulders wear out early and become vulnerable to injury; this is documented by numerous studies.

What has been less well recognized is that weight gain is a major contributor to these injuries. Consider this scenario: You have an SCI, which leaves you with fewer intact nerves to work with. Metabolism and energy expenditure are reduced after SCI, so it's hard to burn calories and easy to store fat. You're getting older, so your physical reserves are dwindling. By now, you've overworked your extremities with wheeling and transfers for a couple of decades. If you then gain 30 new pounds - and wheel and transfer them around - you're a candidate for injury. Well, now that we know about weight gain and its connection to injury, what should we do about it? That's what we don't know.

Able-bodied people at risk of injury are commonly advised not to lift heavy loads. But if you have an SCI, your own body is the load in question. The title of an early film about SCI, *Gravity Is My Enemy*, says it all. Unless you have a very high injury, it's almost impossible to avoid lifting.

Profound Impacts

If an injury does occur, its impact can be formidable. If you have trouble transferring to car, bed, or toilet, or wheeling is too painful, it can be life-changing. If self-care activities become too difficult, independence is lost. And when independence deteriorates, many believe quality of life does, too.

Weight gain doesn't always result in injury, but excess pounds can cause other problems. Some people have become so obese they can no longer manage their own bowel programs, a major sacrifice of independence. It's hard to perform bladder care with a large gut in the way, or even to tie a shoelace. A bulkier body may no longer be able to use standard seating in theaters and airplanes or fit behind the steering wheel of a car, and if an oversized wheelchair is needed, it won't fit through too many doorways. Weight gain can even create a need for personal-assistance services, a lifestyle change that few people find trivial.

It's expensive to be overweight. If you require specialized mobility equipment for getting around, you need wealth. Vans, power chairs, and lifts put you in the same consumer category as people who buy sailboats and play polo. Personal-assistance services and home modification are other big-ticket items. And if weight gain impairs the ability to work, how will these new costs be met?

IT'S NOT WORTH THE WEIGHT!

Finally, your new equipment may not do as much for you as your old gear did. Most handicap-parking spaces are too narrow for vans and lifts, and many covered parking garages are too low. Power chairs are klutzy indoors. Lifts break down. The hard truth about equipment is that the more specialized it gets, the fewer things it does well. Clearly the costs of unrestrained weight gain - even excluding injury - can get extremely high.

Quads, Too

It's convenient to go through life thinking an injury won't happen to us - even after SCI proves us wrong. And it's tempting to think that upper-extremity injury is only a problem for active paraplegics. Not so. A 1993 study at Rancho Los Amigos, published in Archives of Physical Medicine and Rehabilitation, found that in a group of 239 people with SCI, average 12.1 years postinjury, 55% of the quadriplegics reported pain in the shoulders, and 15% in the elbows, wrists, or hands. The message is clear: Upperextremity injury and pain are commonplace in long-term SCI at most injury levels. And quads. too, gain weight, thus predisposing themselves to further injury and loss of function.

Medicine (painkillers, antiinflammatory drugs, splinting, rest, physical therapy, and surgery) offers some help for injuries. However, the treatment is seldom definitive and usually arrives after the damage is done.

Prevention is needed. But how? Survivors of SCI don't always welcome new limitations, even self-imposed ones. So injury often becomes chronic; when it does, so does pain. Pain is yet another incentive to avoid activity, so lifestyles become even more sedentary and further weight gain follows. And if all these cumulative changes cause depression and lack of assertiveness, and they can, then weight gain becomes a hard trap to avoid. It's a vicious circle.

Preventing Weight Gain

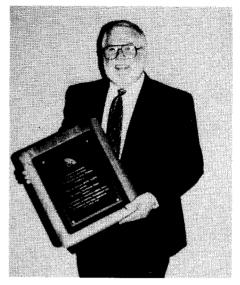
The two standard components of responsible weight-loss programs are exercise and diet. They work for able-bodied people and for most individuals with SCI. Exercise programs need to be done right, but most people with SCI can reduce their weight through this classic combination.

However, for some people with SCI, and especially those aging *Continued on page 7*

BEN HOLLIS 1994 CLINICAL PERFORMANCE AWARD RECIPIENT

Ben Hollis, LCSW, SCI Coordinator at the John L. McClellan Veterans Administration Medical Center in Little Rock, was awarded the 1994 Clinical Performance Award by the American Assn. of Spinal Cord Injury Psychologists and Social Workers at their conference in Las Vegas. Mr. Hollis was honored as the first recipient of this prestigious award. The Clinical Performance Award recognizes a Social Worker or Psychologist who demonstrates outstanding performance in the area of clinical skill related to the psychosocial adjustment and rehabilitation of persons with spinal cord injuries, including outstanding clinical contributions and expertise in the work environment and the community.

Hollis, an Arkansas native (Clay County), completed his Bachelors degree at State College of Arkansas (UCA) and Masters degree at Barry College in Florida. Ben has spent most of his professional career working with veterans with spinal cord injuries, beginning in Florida and Pennsylvania before returning to Arkansas in 1989. He is a frequent speaker at national meetings and has been integrally involved in the training of new SCI Coordinators for the VA, as well as in the development of an SCI registry for the VA. Here in Arkansas, Ben is a charter member of the Arkansas Spinal Cord Injury Association, has been involved in numerous advocacy efforts and serves on several advisory boards and committees.



As AASCIPSW President Helen Bosshart said in presenting this award, "this is long overdue recognition for a job well done." The staff of the Arkansas Spinal Cord Commission add their congratulations to Ben Hollis on this well deserved award.

AGING AND SCI

Continued from Page 6

with overuse injuries, exercise can be a problem. If you're one of those people, it may not be possible to maintain an effective exercise program without risking new injuries or aggravating old ones. In this case, diet is a basic tool for weight reduction. And a sensible diet, unlike exercise, is something every person with SCI can achieve.

Taking off the pounds by dieting "definitely can be done," says Jean Cassidy, R.D., dietitian at Craig Hospital, but, she adds, it won't be effortless. She recommends the same low-fat, high-fiber diet favored for able-bodied people with modifications to accommodate medical conditions such as diabetes, skin breakdown, and elevated cholesterol levels. The basic advice? Cut back on fat and empty calories such as those found in alcohol, soda pop, and sweets.

Fruit juices, too, are a threat to

SCI survivors trained in rehabilitation to push fluids. If you drink quarts of cranberry or any other juice every day, you're getting a consistent and concentrated dose of calories from fructose. The point is not to cut down on fluids, just on those loaded with calories.

Cassidy cautions against fasting or eating only one meal a day. Your metabolism is probably already lowered by your SCI and lack of exercise, and eating infrequently only makes the problem worse. The result is you burn fewer calories and store more fat in your body. Instead, eat two or three small meals a day.

People who are highly motivated can go straight to a stringent low-cholesterol, low-fat, calorie-controlled diet, explains Cassidy. But most people are better at negotiating their way to healthier eating. If you can't give up a beer with dinner, maybe you'll drink water instead of soda pop during the day. Pick one or two changes you're willing to make and stick

with them. When these become routine, you can consider adding more.

Learn to read labels, and recognize that even foods labeled "fat-free" may not be low-calorie. Fat-free bakery goods, for example, are usually loaded with sugar.

Most motivated people, says Cassidy, even those who live sedentary lives, can lose weight with diet alone. Finding that motivation is up to them.

The above is a report from the Rehabilitation Research and Training Center in Aging With Spinal Cord Injury, a joint project of Craig Hospital, of Englewood, CO, and the University of Colorado Health Sciences Center in Denver. The center is funded by the National Institute on Disability Research and Rehabilitation (NIDRR). For more information about the project, contact Research Department, Craig Hospital, 3425 South Clarkson Street, Englewood, CO 80110, (303)789-8000.

Reprinted from *Paraplegia News*, October 1994

WANTED: VIDEOS OF HOBBIES, ACTIVITIES

The ASCC Education and Resource Center on Spinal Cord Injury has a new resource review committee. The Resource Review Committee is searching for new materials for the Center, especially videos made by any of our clients who have an unusual talent or hobby (e.g., wheelchair dancing, outdoor activities, etc.) These

videos might be "how-to" demonstrations that other persons with SCI can use for ideas. Please send a copy of your video tape to:

Attn: Karen Schmidt, Information and Resource Coord. AR Spinal Cord Commission 1501 N. University, Suite 400 Little Rock, AR 72207

NEW STAFF

Continued from Page 1

Case Management office, the new voice that you hear belongs to Denise. Another Arkansan who has come home, Denise returned this summer from Jacksonville, North Carolina, where she had worked for many years in the housing industry. Denise's extensive experience and calm demeanor are a welcome addition to the case management program and she enjoys being "home" again.

December brought our fourth addition to the staff. **John Gould** joined ASCC as our VISTA volunteer Peer Support Counselor. A recent graduate of Wright State University with a Bachelors degree in Rehabilitation. John is originally from Dearborn, Michigan. John brings his own personal experience of spinal cord injury, as well as his education and knowledge, to the Peer Support position and looks forward to getting the program rolling again in the coming months. An accomplished athlete, John is the newest member of the Rollin' Razorbacks as well as a recent competitor in the National Wheelchair Tennis Tournament.

We look forward to working with each of these individuals and know that you will too.

Calendar of Upcoming Events

The National Wheelchair Basketball Assn. Sectional Tournament will be held March 11-12 at the Sylvan Hill High School. For additional information call 834-8513.

AR Disabled Sportsmen Association is having a Trap Shoot on March 24, 1995, starting at 10:00 am at the Remington Plant, Lonoke, AR. For details, contact Karen Schmidt at 296-1792.

Disability Support/Fellowship Meeting at the Oasis Renewal Center, 14913 Cooper Orbit Road, Little Rock, AR, every Tuesday. Local transportation can be arranged. Supper served at 6pm, donations accepted. For more infromation call the Oasis at 225-6890.

To have activities announced in the April '95 issue of Spinal Courier, call the Editor at 296-1784 by 3/24.

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SPINAL COURIER

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